A STRATEGY

FOR

ALZHEIMER DISEASE

AND

RELATED DEMENTIAS

IN

SASKATCHEWAN

REPORT OF THE

PROVINCIAL ADVISORY COMMITTEE OF OLDER PERSONS

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PURPOSE

Alzheimer Disease is the leading cause of dementia and has a devastating impact on individuals and their families. Alzheimer Disease is a progressive degenerative brain disorder that affects an individual's mental and physical abilities and behaviour by destroying vital brain cells. An estimated 420,000 Canadians over the age of 65 have Alzheimer Disease or a related dementia.[1] That is an increase of about 20 percent since the mid 1990's. In Saskatchewan it is projected that in January of 2005 over 18,080 residents will have Alzheimer Disease or a related dementia.[2]

In this report the term ADRD will be used to refer to Alzheimer Disease and related dementias. Related dementias may include such conditions as Vascular Dementia, Creutzfeldt-Jacob Disease, Pick's Disease, or Lewy Body Dementia. (Appendix A: A Description of Alzheimer Disease and Related Dementias)

Aging is the highest risk factor for developing ADRD. Saskatchewan population projections show an increase in the age 65 and over population from 14.4 percent in 2000 to 19.5 percent by 2021. The percentage of Saskatchewan residents age 65 and over per Regional Health Authority range from 3.5 percent in Athabasca to 22.0 percent in Sunrise. (Saskatchewan Health, 2004)

By 2031, Canada's biggest demographic group, the baby-boomers, will move into the age of highest risk for developing ADRD. It is estimated that by that time, the number of Canadians who will have ADRD will have more than doubled from the 2001 figure of 364,000 – to 750,000.

The economic costs of ADRD are startling. An estimated $5.5 billion a year is spent on persons with ADRD in Canada.[3] The most significant cost is for institutional supportive care, that is, long-term care institutions and home care. These costs are predicted to escalate to over $12 billion by the year 2031.[4] The economic burden of dementia is significant not only for individuals with dementia, their families and friends, but also for society.

In recognition of the need to address the emerging problems related to the growing aging population and the projected increases in the number of people with ADRD, the Minister of Health established the process for the development of a strategy for Saskatchewan. The work was undertaken by the Provincial Advisory Committee of Older Persons (PACOP) through an Alzheimer Sub-Committee. Saskatchewan is the last province in Canada to develop a Strategy for Alzheimer Disease.

The mandate of the Alzheimer Sub-Committee was to develop a document that would provide a guide to assure the best possible care and support throughout the continuum of care for those individuals affected by ADRD, their families, their caregivers, and their communities.

For over two years, stakeholders from across the province worked under the Alzheimer Sub-Committee to research the issues, consult with health care professionals, and get input from individuals with Alzheimer Disease, their families and caregivers, to create a document that presents strategic issues, goals and actions.

This document entitled A Strategy for Alzheimer Disease and Related Dementias in Saskatchewan, which will hereafter be referred to as the Alzheimer Strategy, includes seven strategic issues:

- Public awareness and education.
- Guidelines for diagnosis and treatment.
- Support for people with ADRD and their caregivers.
- Supportive environments that allow people to live as independently as possible throughout the disease process.
- Programs and services available across the continuum of care.
- Education and training, and
- Support for biomedical, psychosocial and efficacy based research.

Beyond the major strategic issues there are also underlying themes that emerged throughout the consultations. It was noted that:

- There is a stigma attached to ADRD.
- There is a general lack of understanding of ADRD and the resources required to provide needed care.
- The care system is driven by crisis.
- Services are not always readily available at any given stage, including when the caregiver has difficulties or can no longer cope.
- Urban centres generally have more services, but rural areas have an informal caregiving network among neighbours and friends that assists them in caring for the person with ADRD.
- People with ADRD should be supported to stay at home for as long as possible.

The primary goal of the Alzheimer Strategy is a high quality of life for people affected by ADRD.

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[1]Canadian Study of Health and Aging Working Group: Canadian Study of Health and Aging: study methods and prevalence of dementia. *Can Med Assoc J* 1994; 150: 899-913. And personal communication, CSHA.

[2]Ibid.

[3]Ostbye T, Crosse E. Net economic costs of dementia in Canada. *Can Med Assoc J* 1994; 151 (10): 1457-64. And personal communication, Canadian Study of Health and Aging.

[4]Alberta Health and Wellness Document (July 2002) Alzheimer Disease and Other Dementias, Strategic Directions in Healthy Aging and Continuing Care in Alberta P.1.

BACKGROUND TO ALZHEIMER DISEASE STRATEGY DEVELOPMENT

In October 2002, the Minister of Health requested the Provincial Advisory Committee of Older Persons (PACOP) in collaboration with the Alzheimer Society Of Saskatchewan to develop a strategy for Alzheimer Disease and related dementias for Saskatchewan. The Alzheimer Sub-Committee was co-chaired by a representative of PACOP and a representative of the Alzheimer Society Of Saskatchewan and was provided with consultative and secretariat services by Saskatchewan Health.

The mandate of the Alzheimer Sub-Committee was to develop a strategy that would provide a guide to assure the best possible care and support throughout the continuum of care for those people affected by ADRD, their families, caregivers, and communities.

Initially the Alzheimer Sub-Committee established working groups that represented individuals, professionals and organizations that are interested in ADRD. Representatives included provincial organizations, regional health authorities, health professionals, seniors, individuals with ADRD, their families and other caregivers. (Acknowledgements)

SUMMARY OF THE PROCESS

The Alzheimer Sub-Committee developed a work plan that included:

- a literature review
- working groups
- consultation, and
- strategy development

Literature Review: The Alzheimer Sub-Committee oversaw a review of the literature on evidence, trends, best practice, service delivery models and research regarding ADRD in Saskatchewan, other provinces and countries. Relevant material was forwarded to the Working Groups to assist in their work.

Working Groups: Four groups were established (Acknowledgments), each responsible for a defined segment of the continuum of care as follows:

Working Group A – Prevention to diagnosis

Working Group B – Diagnosis to need for direct service

Working Group C – Direct health service to long-term care placement

Working Group D – Long-term care placement to end of life

The role of each group was to:

- Develop an inventory of existing programs and services,
- Review the information from the literature review relevant to their group,

- Identify gaps in programs and services, research and education,
- Report findings to the Alzheimer Sub-Committee.

Consultation Phase: Focus groups were conducted within each regional health authority in November 2003 and January and February of 2004 to obtain public input from formal and informal caregivers. Consultation with health care professionals was conducted at a focus group at the Alzheimer Society annual provincial conference in October 2003 and input was sought from physicians via focus groups conducted on Telehealth. In total 338 participants attended 15 focus groups.

Strategy Development: Seven strategic issues emerged from the information gathered from the Working Groups and the focus groups. Committees were formed to develop goals and actions related to these issues. The draft document developed was circulated to working group members, focus group participants, Alzheimer Society members and interested stakeholders for feedback.

The document entitled A Strategy for Alzheimer Disease and Related Dementias in Saskatchewan is the result of this process. This document was presented to the PACOP on December 6, 2004.

A Strategy for Alzheimer Disease and Related Dementias in Saskatchewan

This strategy embraces a person-centred philosophy that is articulated through a vision, and values:

Vision

The people of Saskatchewan with ADRD and their families and caregivers experience a good quality of life, comparable to other members of their communities.

Values

Independence/Self Determination: Being in control of one's life, being able to do as much as possible for oneself and making one's own decisions. If unable to participate, the known values and wishes of the person with ADRD must guide all decisions.

Dignity: The right to be treated with respect and to be treated as a person.

Security: The opportunity to live in an environment that is safe, supportive, restraint-free, and wherein one is protected from exploitation and abuse.

Compassion: The right to be treated with concern, understanding, and support.

Strategic Issues

The following goals and proposed actions are presented as the outcome of the accumulated efforts of the working groups, public and professional consultations, and the subsequent discussions and deliberations of the Alzheimer Sub-Committee. Seven strategic issues emerged consistently throughout the process and provided a framework for the presentation of the goals and proposed actions that were developed. It is important to note that the strategic issues are not presented in order of importance.

1. Public Awareness and Education

The people of Saskatchewan do not have an adequate knowledge or understanding of the warning signs of ADRD. In order for people with ADRD and their caregivers to seek early intervention, they must know the basic facts about the disease, where to access information, how to find support and where to contact services. Furthermore, the perceived degree of community understanding, acceptance and awareness of ADRD can affect the willingness of those with ADRD and their caregivers to seek assistance. An Ipsos-Reid Poll[1] conducted by the Alzheimer Society of Canada in 2002 indicates that 87% of Canadians are familiar with ADRD. This poll also indicates that 81% of Canadians feel that they would be looked upon or treated differently if people knew that they were diagnosed with ADRD, demonstrating that there is stigma attached to the diagnosis of ADRD.

The findings from the Alzheimer Strategy consultation indicate that public awareness is a high priority and that there are strong feelings of stigma attached to ADRD. Participants also maintained there is a general lack of understanding of the disease and its progression which may result in people with ADRD and their caregivers becoming isolated.

Goals	Actions
Residents of Saskatchewan are aware of and understand ADRD and know what resources and services exist and how to access these supports.	• Develop a provincial public awareness campaign that focuses on early warning signs, the benefits of early diagnosis, treatments and needs of caregivers. • Develop comprehensive lists of resources and services. • Expand and widely advertise contact information to allow people to access information, resources and services. • Increase resources to produce, distribute and widely circulate standardized print materials for awareness, information and education.

"I think there is a fear in some people, in becoming involved with someone with Alzheimer Disease, not a great fear but a misunderstanding about what people are facing, in my case I found a lot of people dropped back because they just don't know what I am going through, don't want to get involved, don't know what to do."

Focus Group Comment, Regina

[1]Ipsos-Reid poll conducted on behalf of Alzheimer Society of Canada, 2002

2. Diagnosis and Treatment

The inability to identify and recognize the warning signs of ADRD by individuals, family members and/or physicians can be a barrier to diagnosis. Early diagnosis is important because recent advances in Alzheimer research have made medication available to treat the symptoms in people with mild to moderate Alzheimer Disease. Early diagnosis provides individuals and their families with the opportunity to plan for the future, to understand the disease and its progression, to receive treatments, to seek support and to promote the potential for a healthy quality of life.

Information gathered in the Alzheimer Strategy consultation process identified a need for a timely, standardized method of diagnosis with a follow-up protocol that provides individuals with ADRD and their families with access and referral to information and support resources.

Goals	Actions
People with warning signs of ADRD have access to a timely diagnosis using a standardized process.	• Promote the use of, and circulate, existing guidelines for the diagnosis and management of ADRD, such as the Canadian Consensus Guidelines and the Diagnosis and Management Guidelines developed by the Alberta Medical Association. • In addition to physicians, use alternative health practitioners such as advanced clinical nurse practitioners, occupational therapists and primary health care teams to assist with assessments leading to diagnosis. • Develop guidelines for physician referral to specialists to assist with the diagnosis. • Develop a physician payment system for the diagnosis and treatment of ADRD that reflects the amount of time required to complete assessments. • Develop a strategy for the recruitment and retention of specialists, e.g. geriatricians, neurologists.
Health care practitioners, including physicians, provide information and support at the time of diagnosis or refer patients for information and support.	• Provide health care practitioners with easy access to information on existing education and support materials in order to complement their efforts in caring for individuals and families affected by ADRD. • Explore and develop a program similar to the First Link program (Appendix B) offered by the Alzheimer Society of Ottawa, which provides support and education for persons with ADRD and their families. • Increase physician awareness of the programs and services offered by the ASOS.

Residents of Saskatchewan have access to ADRD treatment medications, (e.g. cholinesterase inhibitors or cognitive enhancing medications) which are approved by Health Canada.

- Review the current listings under Exceptional Drug Status (EDS) with the Saskatchewan Drug Plan to ensure that barriers to access and use of medications are eliminated. (Examples of those barriers are: the scoring requirements on the MMSE or FAQ; the frequency of reviews; the restriction of patients to try other medications after a trial has been unsuccessful; and/or the fact that the amount of compensation is a disincentive for doctors to initiate or continue the EDS process.)
- Review and make recommendations on the present policy that restricts the use of anticholingergic activity medications concurrently with Alzheimer medications (Saskatchewan is the only provincial jurisdiction with this restriction).

"It was like climbing a mountain to get a diagnosis."

Focus Group Comment, Weyburn

3. Support for Individuals and Caregivers

The Canadian Study of Health and Aging[1] (1994) shows that approximately 50% of persons with ADRD in Canada live in the community, with almost all of those (94%) being cared for by family and friends.

Increasing numbers of people over 80 years of age and the corresponding increase of those with ADRD suggest a need to examine how services such as home care can support individuals with ADRD and their unpaid caregivers.

During the last decade, the allocation of funding to home care has not kept pace with the increased demand on home care programs. Home care programs have responded to increased pressures for their services by attempting to meet the more pressing needs of short-term post-acute clients, resulting in less capacity to serve long-term clients. Supportive home care services (e.g. housework assistance) have been reduced or eliminated.[2] The result of these changes has been a shifting of the responsibility and cost to clients, family members and other unpaid informal caregivers.

Current statistics from the Alzheimer Society of Canada indicate that 36% of caregivers in the community are over the age of 70. Symptoms of depression are nearly twice as common in ADRD caregivers. People with dementia have fewer friends and relatives to count on beyond their primary caregiver than do seniors without dementia. These statistics are a strong indicator that support services to caregivers of people with ADRD are essential to maintain quality care for the person with ADRD as well as the physical and emotional health of his/her caregiver.

Goals	Actions
People with ADRD and their caregivers have access and support to attend and participate in ongoing education and support services.	• Encourage the use of existing education programs for the person diagnosed with ADRD and their caregivers/families as developed by the Alzheimer Society, such as Between Ourselves Program and the Family Education Series. • Expand support groups, information and counseling services for people with ADRD and their families.
Policies support and recognize the role and commitment of informal caregivers.	• Develop and expand family responsibility leaves from employment to include family members caring for individuals with ADRD. • Develop and expand options that allow caregivers to choose providers and to manage care for their family member. • Promote and expand the Individualized Funding option (Appendix C) of the Home Care Program to include care by family members. • Introduce measures that will allow income tax deductions for caregivers' costs.

[1]Canadian Study of Health and Aging Working Group: Patterns of caring for people with dementia in Canada, Canadian Journal on Aging, 1994, Volume 13, Number 4, pages 470-487.

[2]Forbes, D.A., Stewart,N., Morgan, D., Anderson, M., Parent, K., Janzen, B., (2003). Individual determinants of home care nursing and housework assistance. Canadian Journal of Nursing Research, 35(4), 14-36

Caregivers have access to services and supports at the community level that are based on the caregiver's needs, are flexible and reflect a person-centred approach to care.

- Develop a program that links the individual with ADRD and their families to services in the community and the Alzheimer Society, for example First Link (Appendix B).
- Identify a tool to measure and recognize caregiver stress.
- Listen and respect caregivers' self-evaluation of depression and/or stress and provide appropriate information, counseling referrals, and follow-up.
- Ensure that community supports and services (Appendix C) are in place, such as:
  - adequate and responsive respite (night, in-home, emergency),
  - adult day support programs and
  - home care services.

"Respite care and adult daycare programs are very helpful in reducing stress on the families and other community supporters of persons suffering dementia, reducing the likelihood of caregiver burnout and making it possible for the person with Alzheimer's or other dementia to live in their home longer before having to access ongoing facility based care."

"The more you understand, the better you deal with it."

Focus Group Comments, Saskatoon

4. Supportive Environments

In Canada, approximately one half of people with ADRD currently reside in their own homes; the remaining half live in institutions (Alzheimer Society of Canada, 2002). For people experiencing early symptoms, family caregivers are usually able to provide adequate care for people with ADRD. For people experiencing mid to late-stage symptoms, family caregivers are often unable to provide the quality and level of care that is required. In the advanced stages of the disease, many people with ADRD are admitted to long-term care.

People with ADRD have a right to live in environments that best support their safety and quality of life. A diagnosis of ADRD does not automatically mean that people are incapable of living on their own. It is important that people with ADRD are allowed to live as independently as possible in their own homes. It is equally important that long-term care facilities and supportive housing units provide environments that are "home-like" and are designed to support people with ADRD to maximize independence and quality of life.

> *"We know our nursing homes are not meeting the needs of our people and it will be a bigger issue in the future."*
>
> *Focus Group Comment, Regina*

Goals

Residents of Saskatchewan diagnosed with ADRD are supported to live as independently as possible throughout the disease process.

Actions

- Provide flexible, adequate and responsive social programming and community support services for the person with ADRD living at home.
- Explore new models for the delivery of home care services.
- Provide adequate, responsive, affordable and accessible transportation as an alternative to driving for people with ADRD, who are no longer safe drivers or are unable to drive.
- Ensure that risk assessment tools are available that both determine a person's ability to live independently and recognize an individual's personal tolerance for living at risk.
- Maintain and expand resources and programs, such as the SAIL program (Saskatchewan Aids to Independent Living) that assist individuals to remain in their own homes (Appendix C).
- Provide adequate and responsive homemaking and home maintenance services through home care services to assist people with ADRD to remain independent.

Affordable subsidized housing options are available to people with ADRD that accommodate the needs of people as the disease progresses.	• Develop and maintain housing options that accommodate "aging in place." • Develop a guide to home renovation programs including an inventory of all subsidized renovation assistance programs and how to access them. • Develop housing options to address the gap between living at home and living in a long-term care facility. • Maintain and expand supportive housing options for seniors with ADRD and their care givers.
Long-term care facilities are designed to meet the needs of residents with ADRD.	• Mandate personal care homes and long-term care facilities that care for people with ADRD to embrace: a person-centred model of care and a home-like, safe, secure physical environment specifically designed to care for people with ADRD (Appendix D). • Develop mechanisms to promote and disseminate information on environmental best practices for long-term care facilities and personal care homes. • Provide an adequate number of consultants to monitor facilities to ensure that standards/guidelines are observed and practiced. • Provide behaviour management consultants/specialists to provide expert advice on the standards and guidelines for care of individuals with ADRD in long-term care facilities. • Challenge and resolve contractual/ management practices regarding staff assignment that may discourage consistency or choice of care provider in long-term care facilities.

"The design of this facility creates anxiety in people with dementia: "hospital-like", not "home-like"."

Focus Group Comment, Saskatoon

5. Programs and Services

There is clearly a need for consistent and accessible services that are responsive, flexible and adaptable to the individual needs of people affected by ADRD. A continuum of services should be available that includes; maintenance of an individual in the community for as long as possible; meaningful activities for the person with ADRD; respite services for the caregiver; on-going medical support and treatment; and housing options, other than long-term care, for those that can no longer be maintained in their own homes. The cost or fees for the services should not be a deterrent to their use. Recognition needs to be given to the needs of both rural and urban communities.

All services should have a crisis prevention component that would provide timely support for individuals with ADRD as well as preventing the isolation of the care provider. Limitations in quality of care and a lack of support often result in premature placement in long-term care facilities. Services must be provided in the home as needed.

> *"It is like a mine field, you really need to have a social worker to give you help and you must have someone to help you to get through. If you don't have someone advocating for you, you are lost, especially if you don't know how to work through the system."*
>
> *Focus Group Comment, Prince Albert*

Goals

Residents of Saskatchewan have at their disposal a continuum of services that are sensitive to and supportive of the needs of individuals with ADRD and their families/caregivers. These services (Appendix C) will include, but not be limited to:

- Home care services – nursing, homemaking, personal care
- Support and education groups
- Adult day support programs
- Respite services – day, night, emergency and in-home
- Counseling services
- Palliative care

Actions

- Develop, distribute and mandate a philosophy of care, such as the Alzheimer Society's "Guidelines for Care" (Appendix D) document that supports a person-centred approach to care.
- Provide guidelines and standards of practice for the treatment, care and support of persons in all programs and facilities that serve those with ADRD.
- Identify barriers to the effective delivery of services or treatments to people with ADRD and develop a strategy to overcome the barriers.
- Provide services that adopt and include palliative care principles for people in the final stages of life regardless of their living arrangement and diagnosis.

All services offered across the continuum of care demonstrate high quality dementia care, are timely, flexible, provide bridges between services, and anticipate change.

- Review the criteria for services to determine if they could be offered 'earlier' to the family in need.
- Expand options to engage individuals with early memory loss in order to introduce them to the continuum of services available.
- Expand respite options to include in-home respite, night respite and emergency respite.
- Explore new models for the delivery of respite services, such as multi-family designation of additional beds in long-term care facilities.
- RHAs will identify and change program policies or procedures that act as barriers to inter-program communication and coordination of services.

"One of the most difficult things for us was, what to do and who to contact. It took two and a half years to know about the Day Program, the Doctor didn't know where to go, we need this information right at the start of the diagnosis."

Focus Group Comment, Regina

6. Education and Training

The projected rise in the number of people in Saskatchewan who will be diagnosed with ADRD illustrates the need for an increase in specialized education and training regarding the diagnosis, management and care of individuals with ADRD. Physicians, other health care practitioners and informal caregivers participating in focus groups identified the need for specialized training as a priority.

Since the majority of people receiving care in institutions have some form of ADRD, core competencies in ADRD care that reflect best practices need to be developed and incorporated into education and training curricula for professional care providers. Education curricula should reflect a person-centred model of care.

> *"I would like to see mandatory and ongoing education for all staff in long-term care."*
>
> *Focus Group Comment, Swift Current*

The resources for the ongoing development, maintenance and upgrading of individual skills and knowledge should be available for professional and other care providers.

Goals	Actions
Academic curriculum content incorporates education and training on ADRD and is provided to students in applicable professional health care related programs.	• Develop partnerships with educational institutions in Saskatchewan to promote the increase of education hours on the subject of ADRD. • Educate physicians and health care practitioners on best practices in diagnosis and treatment.
Standards for entry-level para-professionals working with people with ADRD.	• Increase training and education for paraprofessionals through the availability of courses or programs that prepare them for work with individuals with ADRD.
Professionals and paraprofessionals working with people with ADRD are trained to identify and prevent elder abuse.	• Provide training and workshops to staff in all services about the lack of tolerance of any form of elder abuse. • Train staff in alternatives to intrusive interventions and use of restraints (physical, chemical and environmental).

Consistent continuing education for health care professionals and paraprofessionals.	• Develop partnerships with the continuing education component of professional organizations to meet ongoing needs of professional groups for current, evidence-based education about ADRD. • Provide managers and supervisors in institutional supportive care facilities with increased training regarding specialized care, leadership and supervision in the delivery of person-centred care. • Educate health care professionals and paraprofessionals together in order to promote the application of team work and best practices in ADRD care.

"Staff have a wonderful attitude, takes a special person, they have a lot of training – but no matter what the training it takes a special person."

Focus Group Comment, Regina

7. RESEARCH

Despite the advances in research, both the cause and the cure for ADRD remain unknown. Currently, an estimated 364,000 Canadians over 65 have Alzheimer Disease. In January 2005, an estimated 420,000 Canadians over 65 will have Alzheimer Disease or a related dementia. It is estimated that more than 509,000 Canadians will be diagnosed with Alzheimer Disease by the year 2031 if a cure is not found. This makes the disease an urgent research priority.

Only through research shall we discover ways to make earlier and more accurate diagnoses, more effective treatments and, ultimately, find the cure. Research will also help us develop the best methods of caring for individuals with ADRD, as well as their caregivers.

Saskatchewan is the first province to establish a Health Quality Council (HQC). The HQC is an independent agency that measures and reports on quality care, promotes improvement and engages its partners in building a better health care system in Saskatchewan. The HQC has initiated several projects that have a direct impact on the treatment of people with ADRD.

The Saskatchewan Health Research Foundation (SHRF), created in 2003, is responsible for facilitating and promoting research in Saskatchewan.

Goals	Actions
Individuals with ADRD and their caregivers have access to new and improved treatments, support, interventions and supportive environments that promote and enhance their quality of life.	• Increase the amount of funding for ADRD research. • Work in partnership with HQC to establish priorities to address identified issues in this document.
Guidelines and best practices in the treatment and care of those with ADRD and their caregivers are available.	• Utilize the HQC and their resources to establish evidence-based guidelines and best practices for dementia care in Saskatchewan.
Saskatchewan discovers a cause and a cure for ADRD.	• Saskatchewan Health Research Foundation will devote increased biomedical and psychosocial research funding to the study of dementia by developing partnerships between governments, the private sector and non-government organizations.

SUMMARY OF KEY FINDINGS

Based on the seven strategic issues, goals and potential strategies, the Alzheimer Sub-Committee identified the following as priority areas for action by Saskatchewan Health, the Alzheimer Society Of Saskatchewan and other stakeholders.

1. ***Public Awareness and Education***

   Residents of Saskatchewan need to have an awareness and understanding of Alzheimer Disease and related dementias, knowledge of resources and services in the community and understand the process to access these supports.

2. ***Diagnosis and Treatment***

   People with warning signs of Alzheimer Disease and related dementias should have access to a timely, standardized diagnosis as well as access to treatments that will manage the symptoms of Alzheimer Disease and related dementias.

3. ***Support for Individuals with Alzheimer Disease and their Caregivers***

   Support and education services for people with Alzheimer Disease and related dementias and their caregivers should be available across the province.

4. ***Supportive Environments***

   Residents of Saskatchewan require support to live as independently as possible throughout the disease process.

5. ***Programs and Services***

   Residents of Saskatchewan need to have available a continuum of services that are sensitive to the needs of the person with Alzheimer Disease and related dementias and their families and caregivers

6. ***Education and Training***

   Health practitioners including physicians and other care professionals should have core competencies in Alzheimer Disease and other related dementia care and ongoing education and training that result in sensitive, competent and high quality of care for persons with Alzheimer Disease.

7. ***Research***

   Support for biomedical, psychosocial and service efficacy is expected in Saskatchewan.

APPENDIX A

A DESCRIPTION OF ALZHEIMER DISEASE AND RELATED DEMENTIAS

Dementia is a syndrome consisting of a number of symptoms that include a decline in memory, judgment and reasoning, and changes in mood, behaviour and communication abilities.

Alzheimer Disease, the most common form of dementia accounts for 64 per cent of all dementias in Canada. The features of Alzheimer Disease include a gradual onset and continuing decline of memory, as well as changes in reasoning and judgment and inability to perform familiar tasks. The specific cause of Alzheimer Disease is unknown. At present, there is no cure for Alzheimer Disease and no treatment to stop its progression. Several medications are available that may be used to manage some of the symptoms. The treatments do not work for everyone and are effective for a limited time. However, by understanding the person's personality, life experiences, support systems and ways of coping, an approach to care can be created that preserves the individual's quality of life.

Related dementias (other than Alzheimer Disease) may be demonstrated through symptoms of sudden onset of memory problems, early behaviour problems, or difficulties with speech and movement. Causes may be related to Vascular dementia, Creutzfeldt-Jakob Disease, Lewy Body Dementia or Pick's Disease.

1. The Effects of Alzheimer Disease and Related Dementias

Alzheimer Disease and related dementias affect individuals differently and eventually affect all areas of a person's life – how he/she thinks, feels and acts. Although the disease results in changes, it does not affect the person's ability to appreciate and respond to feelings such as joy, anger, fear, love or sadness.

It is difficult to predict the symptoms each person will have, the order in which they will appear or the speed of the disease progression. The disease may affect the following:

1.1 Mental Abilities

- a person's ability to understand, think, remember and communicate will be affected
- a person's ability to make decisions will be reduced
- simple tasks will become more difficult or be forgotten
- confusion and memory loss, initially for recent events and eventually for long-term events, will occur
- the ability to find the right words and follow a conversation will be affected

1.2 Emotions and Moods

- a person may appear uninterested and stop hobbies or other activities
- a person may quickly lose interest in the middle of a task
- the ability to control emotions might be lost
- a person may become more withdrawn or have less expression

1.3 Behaviour

Changes in the brain may bring about changes in the way the person reacts to his or her environment. The reactions may seem out of character for the person. Some common reactions include:

- a person may react differently to his/her environment due to the changes in the brain
- a person may repeat the same action or words over and over again
- he/she may hide possessions
- a person may become restless or have physical or verbal outbursts
- a person may act "out of character" or inappropriately in a social setting

1.4 Physical Abilities

The disease may affect a person's physical co-ordination. As the disease progresses, there may be a gradual physical decline. These changes may impact on the person's ability to independently perform day-to-day tasks, such as eating, bathing and getting dressed.

1.5 Effects on Families and Caregivers

The effects of the disease on the individual also impact families and caregivers. Some caregivers may experience adverse effects on their health. Medical models often focus on the affected individual without recognizing the need to provide support to caregivers.

2. Prevalence of Alzheimer Disease and Related Dementias

The number of residents in Saskatchewan age 65 and over is projected to increase from 14.4% of the total population in 2000 to 19.5% of the total population in 2021. (Statistics Canada, 2001).

In 2005, it is projected that 18,080 residents of Saskatchewan will have Alzheimer Disease or a related dementia.[1] The Canadian Study of Health and Aging estimates that 450,000 Canadians will have Alzheimer Disease or a related dementia in 2007. By 2031, over 750,000 Canadians will have Alzheimer Disease or a related dementia.

Increased age was associated with an increased likelihood of having Alzheimer Disease or a related dementia.[2]

- 1 in 50 between the ages of 65-74
- 1 in 9 between ages 75-84
- 1 in 3 age 85 and older

3. Economic Impact of Alzheimer Disease and Related Dementias

An estimated $5.5 billion a year is spent on persons with Alzheimer Disease and related dementias in Canada.[3]

The annual societal cost of care per individual with Alzheimer Disease is estimated to be:

- $36,794 for severe disease
- $25,724 for moderate disease
- $16,054 for mild to moderate disease
- $9,451 for mild disease[4]

[1]Figure is based on projected estimates in the following study: Canadian Study of Health and Aging Working Group: Canadian Study of Health and Aging: study methods and prevalence of dementia. *Can Med Assoc J* 1994; 150: 899-913. And personal communication, 2004. (Note: The CSHA only surveyed people over the age of 65.).

[2]Canadian Study of Health and Aging Working Group: Canadian Study of Health and Aging: study methods and prevalence of dementia. *Can Med Assoc J* 1994; 150: 899-913. And personal communication, CSHA.

[3]Ostbye T, Crosse E. Net economic costs of dementia in Canada. *Can Med Assoc J* 1994; 151 (10): 1457-64. And personal communication, Canadian Study of Health and Aging.

[4]Hux, M. et al. Relation between severity of Alzheimer's disease and costs of caring. *Can Med Assoc J* 1998; 159 (5).

APPENDIX B

First Link

The Alzheimer Society of Ottawa's First Link project is a direct referral program that provides clients with coordinated support, learning and linkages to community services from the point of diagnosis through the progression of Alzheimer Disease or a related dementia. Working with the Dementia Network of Ottawa, a referral system to First Link was implemented as the next step after a diagnosis of dementia.

Diagnosing physicians inform patients and their families about First Link and fill out a simple referral slip that is faxed to the Alzheimer Society. Patients and families receive a call from the First Link Coordinator in order to establish a link. Families are: given the opportunity to ask questions about the new diagnosis; offered written information about the disease; informed of community supports as needed; and encouraged to participate in First Link learning series, the peer support program and other appropriate supports provided by Dementia Network of Ottawa organizations.

History

In 2001, the Dementia Network of Ottawa identified two gaps in the provision of dementia care in the city of Ottawa. Firstly, many families affected by dementia did not access support services until a crisis situation developed. Secondly, support for families coping with the end stage of dementia was lacking. The First Link program was developed to fill these gaps. The Dementia Network of Ottawa hypothesized that early access to information, education programs and community supports, can enable families to cope more effectively throughout the progression of dementia.

Partnership

First Link is a collaborative project that links all those concerned about dementia care. One single organization cannot adequately support all individuals and families affected by dementia. Individuals with dementia and their families have different needs at different times during their journey. Such a complex illness requires a team of physicians, geriatricians, Alzheimer Society staff, social workers, occupational therapists, and others working together to provide support to individuals with dementia and their family members.

Project Goals

- To ensure individuals newly diagnosed with dementia and their families have early access to learning, services and support.
- To increase effective and efficient utilization of community resources, including those of the Alzheimer Society.
- To reduce overall incidence and intensity of caregiving crisis situations.
- To strengthen the link between diagnosing family physicians, the Alzheimer Society and community service providers.
- To raise community education and awareness about Alzheimer Disease and related dementias.

Results

More than 690 referrals were received by the First Link Coordinator over a 2 year pilot phase of the First Link project. More than 250 different families have participated in First Link learning series, improving their understanding of Alzheimer Disease and dementia and coping skills. Evaluation results indicate that First Link has helped individuals with dementia and their family members in several ways including: learning more about Alzheimer Disease and dementia, linking families to community services, increasing caregivers' confidence in caring for their family member, and helping caregivers to more effectively manage crises. Linkages between physicians, community service providers and the Alzheimer Society of Ottawa were strengthened as all partners worked collaboratively to develop the project. Health care professionals reported that they have a stronger relationship with the Alzheimer Society as a result of the First Link program. Family physicians reported that their patients greatly benefited from First Link.

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APPENDIX C

SERVICES AND SUPPORTS FOR INDIVIDUALS WITH ALZHEIMER DISEASE AND RELATED DEMENTIAS IN SASKATCHEWAN

Saskatchewan provides a variety of programs and services throughout the province to the general population, including individuals with Alzheimer Disease and related dementias (ADRD) and their care providers and families.

Saskatchewan Health, through the Regional Health Authorities (RHAs), provides programs and services to individuals in need of support and intervention due to illness or disability. Individuals with ADRD, their caregivers and families are able to benefit from these programs and services. It is important to note that services in Saskatchewan are generally provided based on need, not diagnosis.

Other government departments, such as the Department of Community Resources and Employment, also provide services that assist people, including people with ADRD, through their housing and financial support programs.

A scan of the programs and services that are available in the province revealed that apart from those provided by the Alzheimer Society Of Saskatchewan, there are relatively few that are specifically designed for those individuals with ADRD.

Currently, in Saskatchewan, individuals with ADRD and their families are eligible to receive services from the following continuum of care provided through mainstream programs and services:

HOME CARE PROGRAM

Home Care is a comprehensive program funded by Saskatchewan Health and delivered by the Regional Health Authorities to people of all ages living in the community. Eligibility for services is based on assessed need. There is a charge for some services while others are covered through subsidies. The Home Care Program provides the supports necessary for qualifying individuals with ADRD and their caregivers to remain in their own home for as long as possible.

Services can include:

- case management and assessment,
- nursing,
- meals,
- therapies (in some regions),
- personal care,
- home management,
- respite,
- limited home maintenance and
- volunteer services such as visiting, security calls, and transportation.

Individualized Funding

Individualized Funding is an option of the home care program that provides funding (based on assessed need) to a person to arrange and manage their own support services, rather than receiving the services directly from the home care program.

Institutional Supportive Care Program (Special Care Homes and Personal Care Homes)

Special Care Homes

Special care homes provide long-term care to individuals in need of heavy care that cannot be met through home-based community services. Some special care homes provide additional services to their region that include: adult day support programming, respite services and palliative care services.

In March 2004, there were 158 licensed special care homes (8,547 beds). Additionally, there are 32 hospitals that provide long-term care beds as part of their service delivery.

Personal Care Homes

Personal care homes provide an alternative residential option for individuals who neither need nor wish to use the services of the publicly funded home care, public housing or special care home systems. The province licenses these homes under the authority of the *Personal Care Homes Act and Regulations*.

In 2004 Saskatchewan had 279 licensed personal care homes with a total of 2,651 beds.

Behaviour Management Consultants

Saskatchewan Health provides funding to the Regina Qu'Appelle Regional Health Authority and the Prairie North Regional Health Authority to employ a Behaviour Management Consultant to provide assistance provincially with planning for difficult to manage clients.

Palliative Care Services

Palliative care services refer to interdisciplinary services that provide active compassionate care to the terminally ill at home, in hospital or in a care facility. This program is integrated into global acute care, home care and institutional supportive care programs and is delivered by the RHAs.

Saskatchewan Aids to Independent Living (SAIL)

Seniors with a long-term physical disability may be eligible to receive supplies and equipment from the SAIL program. Examples include wheelchairs, walkers, home oxygen, artificial limbs and braces.

Saskatchewan Prescription Drug Plan

The Drug Plan, with its formulary, is a provincial program that provides benefits to eligible Saskatchewan residents by promoting cost-effective drug therapy in order to ensure that individuals have access to medications necessary for the maintenance of their health. For individuals with high drug costs in relation to their income, the Drug Plan may provide special support to reduce the financial burden of prescription drugs. Drugs that are not listed on the Saskatchewan Formulary may qualify under Exception Drug Status (EDS). EDS is criteria-based coverage for drug products where the regular benefit listing may not be appropriate or possible.

Coordination and Quality of Care Services

Assessment and Placement Services

Each RHA has staff who will assist individuals with their transition from one placement to another, for example, those people leaving an acute care setting who require either assistance (home care) in their own homes or a placement in a long-term care facility.

Quality of Care Coordinators

Each RHA has a Quality of Care Coordinator (QCC) that has the role to assist individuals and families with their questions or concerns about health services, and to ensure that individuals are informed about their rights and options. The QCC works at a local level with clients and family members to address their care concerns.

Alzheimer Society Of Saskatchewan

Established in 1982, the Alzheimer Society Of Saskatchewan (ASOS) is a charitable organization that provides help and hope to those affected by Alzheimer Disease or a related disorder. The mission of the Alzheimer Society is, "to alleviate the personal and social consequences of Alzheimer Disease and related disorders while they search for a cause and a cure". The Society achieves its mission through support, education advocacy and research.

Alzheimer Society Of Saskatchewan Programs and Services

Support and Information

- ***Between Ourselves – Groups for people with Early Memory Loss*** – this six-week program provides individuals who are experiencing early memory loss an opportunity to learn about Alzheimer Disease.
- ***Information and Counseling*** – staff are available to provide information, counseling and support to people with Alzheimer Disease, families or caregivers.
- ***Support and Information Groups*** – there are over 50 Support and Information Groups across the province. These groups provide information on a wide range of topics pertaining to Alzheimer Disease, and allow participants to share feelings and encourage people to exchange ideas on how to care for people who have Alzheimer Disease.

- ***Lending Library*** – contains a large collection of books and videos on Alzheimer Disease and other dementias. The lending library is accessible on their web site using the Catalogue Cruiser.
- ***Newsletter*** – produced three times a year and sent out to the membership of the Alzheimer Society Of Saskatchewan to provide current information regarding activities, ideas and research.
- ***Web Site*** – provides information on Alzheimer Disease, provincial programs and services, special events, volunteer opportunities, fund development and much more. Visit the web site at www.alzheimer.sk.ca
- ***Information*** – information packages are available to be sent out to any member of the public. Packages contain a variety of pamphlets and information to help individual's families and caregivers.
- ***Safely Home – Alzheimer Wandering Registry*** – a national program that operates in cooperation with the RCMP. Registration with Safely Home is designed to help individuals return home safely after an episode of wandering.

Education and Awareness

- ***Care At Home*** – provides health care professionals with the skills and knowledge they need to work effectively with individuals with Alzheimer Disease and their families. The program consists of seven modules and an examination. A Certificate of Recognition is presented to participants upon successful completion. Care at Home can be completed through in-class sessions or by correspondence.
- ***Police Education*** – provides training for RCMP and City Police recruits on the Safely Home – Alzheimer Wandering Registry Program.
- ***Family Education Series*** – offered to families and friends affected by Alzheimer Disease, this six-week education series provides answers to the questions most frequently asked by families dealing with Alzheimer Disease.
- ***Children's Education Program*** – for grades K to 12, hands on training to teach children and adolescents about Alzheimer Disease.
- ***Speaker's Bureau*** – a group of dedicated staff and volunteers that conduct presentations to promote awareness and understanding of Alzheimer Disease, the Society and their services.
- ***Awareness Month*** – promotes awareness of Alzheimer Disease throughout the province, includes luncheons in Saskatoon and Regina for community leaders and those interested in Alzheimer Disease.
- ***Enhancing Care*** – is a program designed to assist agencies and long-term care facilities to achieve the Alzheimer Society Guidelines for Care through an assessment and goal-setting process.
- ***Annual Provincial Conference*** – an annual education day for paid care providers consisting of topics related to dementia care in Saskatchewan.
- ***Educational Workshops*** – provides education to caregivers, families, professionals, schools, etc.
- ***Presentations*** – provides speakers on any aspect of Alzheimer Disease to professionals, service clubs, schools, etc.

Research

- ***Funding for Research*** – funds research through the Alzheimer Society of Canada Joint Research Program, and the Young Investigators Grant Program. The ASOS also supports research in Saskatchewan at the University of Saskatchewan Neuropsychiatry Research Unit and through the Canadian Institute of Health Research (CIHR), New Emerging Team Grant.

Saskatchewan Provincial Advisory Committee of Older Persons (PACOP)

In June 2000 the Provincial Government established the Provincial Advisory Committee of Older Persons to identify the needs of Saskatchewan seniors and a means of addressing them through government policy. The specific mandate of PACOP is:

- To represent as individuals the views of older persons;
- To share information on issues and practices relating to older persons;
- To identify options to better serve these persons;
- To review and prioritize issues and specific provincial actions to be undertaken; and
- To provide ongoing information to the Minister responsible for Seniors.

Housing

The Saskatchewan Housing Corporation provides affordable, quality housing for low- to modest-income seniors, families and people with disabilities.

Social Housing for Seniors

Social Housing for Seniors is available in more than 280 communities across Saskatchewan. Tenant rents are calculated on a sliding scale based on a tenant's ability to pay. Priority is given to those with the greatest need based on their current housing conditions.

Saskatchewan Assisted Living Services (SALS)

SALS provides a community-based service option for low-income tenants in selected Social Housing projects for seniors. The initiative, managed by the Department of Community Resources and Employment (DCRE), responds to those seniors who desire a combination of shelter and support services to maintain their independence and to remain in their homes.

APPENDIX D

GUIDELINES FOR CARE

Because of its unique nature, people with Alzheimer Disease require specialized care. The Alzheimer Society developed "Guidelines for Care" to assist those who care for people with Alzheimer Disease. The guidelines outline a philosophy of best practices for Alzheimer care.

1. Everyone who cares for someone with Alzheimer Disease should have training relevant to their caregiving role.
2. Everyone who cares for someone with Alzheimer Disease needs support to maintain their caregiving role.
3. Because Alzheimer Disease affects each person differently, an individualized assessment of the person's abilities needs to be completed on a regular basis.
4. A comprehensive care plan should be developed for each person reflecting the person's strengths and abilities.
5. A person with Alzheimer Disease needs to be involved in meaningful daily activities that are based on the person's life history.
6. Community agencies and long-term care facilities require specialized human resources, procedures and protocols in order to provide quality care.
7. The environment plays an important role in maintaining the person's independence and quality of life.
8. Transportation needs of people with the disease require special procedures to ensure safety for everyone.
9. A diagnosis of Alzheimer Disease does not mean that a person cannot continue to make decisions.
10. A person with Alzheimer Disease must be protected from abuse or neglect.
11. No restraint use is the preferred choice for providing quality care for people with Alzheimer Disease.

APPENDIX E

DEFINITIONS

Cholinesterase Inhibitor Drugs: This class of drugs acts by inhibiting the activity of acetylcholinesterase, an enzyme whose function is to break down acetylcholine, resulting in higher levels of acetylcholine in the brain. Acetylcholine is a chemical thought to be important for learning and memory. Some examples of this drug class are donepezil, galantamine, and rivastigmine.

Adult Day Support Program: provide an organized unit of health and social services to non-residents of the special-care home. The main purpose of an adult day program are to maintain and increase the individual's capacity to perform activities of daily living, and to prevent pre-mature long-term institutionalization by offering relief to care providers in the community.

Anticholinergic activity medications: Inhibiting or blocking the physiological action of acetylcholine at a receptor site.

Alzheimer Disease: A progressive degenerative disease of the brain, in which there is a gradual loss of function and death of nerve cells in several areas of the brain. It results in loss of cognitive function such as memory and language, and changes in behaviour, mood and emotion, and physical abilities. Alzheimer Disease is the most common type of dementia.

Caregiver: A person who provides personal care to a person with Alzheimer Disease or a related dementia. Caregivers may be paid (staff and administration of agencies, programs and long-term care settings) or unpaid (family members and significant others, friends and neighbours, and volunteers).

Dementia: A group of symptoms which include the loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with an individual's daily functioning. Symptoms also include changes in personality, mood and behaviour. Dementia is not a disease in itself, but may have many different causes, of which Alzheimer Disease is the most common.

Exceptional Drug Status: A type of listing for drugs under Saskatchewan Health's Prescription Drug Plan. Exception Drug Status is criteria-based coverage for drug products where the regular benefit listing may not be appropriate or possible.

First Link Program: Is a direct referral program that provides clients with coordinated support, learning and linkages to community services from the point of diagnosis through the progression of Alzheimer Disease or a related dementia.

Functional Assessment Questionnaire: An assessment to evaluate ability to perform activities of daily living.

Home Care: A comprehensive program funded by Saskatchewan Health and delivered by the Regional Health Authorities to people of all ages living in the community.

Individualized Funding: An option of the home care program that provides funding (based on assessed need) to a person to arrange and manage their own support services, rather than receiving the service directly from the home care program.

Long-Term Care Facility: Special Care Homes provide long-term care to individuals in need of heavy care that cannot be met through home-based community services.

Mini Mental Status Exam: An assessment to evaluate cognitive functioning.

Paraprofessional: Health care workers with diploma, certificate or on-the-job training who work under the supervision and direction of a health professional.

Palliative Care: Interdisciplinary services that provide compassionate care to the terminally ill at home, in hospital or in another care facility.

Personal Care Home: Provide an alternative residential option for individuals who neither need nor wish to use the services of the publicly funded home care, public housing or special care home system.

Related Dementias: Related dementias are those dementias other than Alzheimer Disease with causes that may be related to Vascular dementia due to stroke, Creutzfeldt-Jakob Disease, Lewy Body Dementia, or Pick's Disease.

Respite: a planned period of temporary care offered in a special-care home to persons who normally reside at home, and who are dependent on family members or other primary caregivers for intermittent or continuous care.

Restraints: A device or medication used to restrict or control a person's movement or behaviour.

- **Physical Restraint:** A manual or physical device that restricts or controls movement or behaviour. They may be attached to the person's body or create physical barriers.
- **Chemical Restraint:** Medications given with a specific and sole purpose of inhibiting a behaviour (e.g. pacing, wandering, restlessness, agitation, aggressive or uncooperative behaviour) or movement and not required to treat the resident's medical or psychiatric symptoms. This includes sedatives, hypnotics, antipsychotics, antidepressants or antianxiety medications.
- **Environmental Restraint:** Barriers to free personal movement which serve to confine residents to specific areas, e.g. a locked door.

Saskatchewan Aids to Independent Living (SAIL): A program of Saskatchewan Health that facilitates the independence of persons with permanent physical disabilities. Benefits include the provision of medical equipment, supplies and services to help achieve a more independent lifestyle.

TeleHealth: Is a Saskatchewan Health Program that provides medical consultation and services to rural or remote areas of the province through videoconference links with designated sites. Health care professionals can use Telehealth for appropriate clinical appointments, consultations, follow-ups, meetings and education sessions.

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